Witness Name: Justine Gordon-Smith
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INFECTED BLOOD INQUIRY

THIRD WRITTEN STATEMENT OF JUSTINE GORDON-SMITH

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 January 2025.

I, Dr Justine Gordon-Smith, will say as follows:

Q1. Please describe the nature of the work which you have been undertaking, in relation to the question of compensation, since the publication of the Inquiry's Report in May 2024.

1. I am recognised as an individual campaigner by both the UK and Scottish Governments, and with IBCA. For at least the last couple of years I have had direct engagement with all these government agencies. I am always labelled as a representative of 'women, carers and estates' in meeting taglines. I do campaign work and lobby government and consider myself an individual member of the Scottish Infected Blood Forum, who's leadership and members approach I respect. I also am a member of the APG on Contaminated Blood in Westminster and have worked with the Haemophilia Society, campaigned with the charity Factor Eight. More recently I have begun a working dialogue with Tainted Blood Siblings and Children's group and have been involved with the Getting It Right Group, having co-authored parts of the document submitted to

the government and IBCA. When I refer to government, I refer to the Cabinet Office and IBCA, which are essentially the same organisation. The term ‘operationally independent’, is a rhetorical misnomer.

2. In 2023 when Jeremy Quinn was Paymaster General, I made a formal complaint to the Cabinet Office about its management of Interim Payments. The government argued that making interim payments to the estates of the deceased was a policy decision, and that therefore I could not complain about Government policy. I also argued about statements made in the House of Commons which misrepresented the second interim reports recommendations on the mechanism for how interim payments could be paid swiftly [WITN2632086]. I argued that since the Inquiry had also recommended interim payments should be made to ‘unrecognised estates’, and that the government had made payments to bereaved widows and partners, that the policy decision had been made, and that the governments inaction was essentially in breach of both the Human Rights Act and the Equalities Act.

3. I had checked my arguments with the Equalities and Human Rights Commission Advice line. I was quite confident that my complaint was legally correct. I had also explicitly explored the Administration of Estates Act 1925, which did not define or distinguish in law that a spouse was any more entitled to be an inheritor of an estate, that any other surviving relative such as a child.

4. As my own family had a historical background in practising law, I come from a position, where I believe that it is quite possible to read legislation, and that anyone with common sense or knowledge of case law can reasonably interpret the law. It is then up to the opposing side to make a counter argument. Except in this case, even by the time my former MP Deidre Brock had sponsored my complaint to the Parliamentary and Health Service Ombudsman, the government did not make any counter argument. Instead, the government metaphorically put its fingers in its ears, and kept on repeating the mantra of ‘it is a policy decision’ which the PHSO was only too happy to regurgitate, as it did not want to investigate my complaint.

5. I then raised the lack of access to a regulator directly with Earl Howe, who was overseeing the passage of the Victims and Prisoners Bill through the House of Lords. Earl Howe raised my case directly with the PHSO, who not only dismissed my complaint, but did so in a manner lacking empathy and/or consideration. At the time the government was arguing that infected blood victims did not need access to the Victim's Commissioner, because we had access to the PHSO. I was able to demonstrate that this was untrue. Infected Blood campaigners still have no access to either the Victims Commissioner, and or the PHSO.

6. I tested this principle quite recently by writing to the Victims Commissioner on the 11th of October 2024, and the response received from Baroness Newlove, on the 5th of November [WITN2632087], confirms that our only course of action other than the courts, is to lobby our member of parliament. There is no regulator and no one that can help us or advocate for us. It has also been commented on by the Infected Blood Community in Scotland and in England, that no one is able to secure support from the recent cohort of Labour MP's.

7. Questions are arising as to whether the new intake of Labour MP's have been instructed by the parliamentary whip's office, not to respond to our community. Report after report is coming in, that regardless of an individual's effort to make contact, a number of MPs from the Labour Party are not responding to constituency inquiries for support. The recent debate for example on the Infected Blood Inquiry Report from the 23rd of November 2024 only had one Scottish MP, Peter Wishart, present, and few other MPs from England, Wales or Northern Ireland which we as a community were shocked by.

8. In previous years there was a body of MP's representing victims, now there are a handful, despite our communities' collective efforts to engage MPs since the General Election. My own MP did arrange to meet with me when she was first elected which was very kind, but the short notice in the way the government called the debate on the final report, and the actual scheduling on the day meant she did not attend, being scheduled to speak on a debate in Westminster Hall on Gaza. Even though this debate, ended one hour and 30 minutes earlier, she

still did not attend later in the session. Some other MPs who were in the Westminster Hall debate did, such as John McDonnell. I attended a drop as soon as the debate had been called in order to urge my MP to attend, and the short notice in the way the debate went meant there was automatically a conflict, so it is my perception that the government is 'managing' engagement in parliament specifically to be seen to engage, without actual engagement. The UK Government is responsible for the compensation scheme and without MP's representing us in parliament, without a regulator, or access to court, since the legal cases are all stayed, the infected blood community is post inquiry being ignored regardless of how much we object to what is unfolding.

9. It may be that I was so used to Deirdre Brock always standing up for us, and her constituency office being so supportive, that this has created an unrealistic expectation. However, given the impact of this scandal on the city and people of Edinburgh, we believe that this is a very serious and important issue, that should, as Deirdre did, be brought up as often as possible. Deirdre asked questions in Business Questions. Deirdre asked questions in Prime Ministers Questions, and she was always submitting written questions to the government and arranging access for us. Deirdre was an active member of the APG. This has all gone.

10. Our MP asked two questions initially before the Autumn recess, but no written questions have been asked to date and the press seems to be in the main regurgitating briefings from the government. The new intake of MP's does not seem to be as engaged as the ones they replaced across the country. I think we all appreciate that it takes time for a new MP to settle in, but there are many MP's, including my own, who still do not have constituency offices 9 months after the last General Election. The government gives the false impression that everything is sorted. They announce a headline figure, of £11.8 Billion, which infers generosity, but the actual compensation scheme not only treats victims like welfare claimants, but it is also being gradually eroded and becoming meaner, and crueller as the civil servants make cuts without any consultation or consideration. Compensation is ultimately still not in the hands of victims. The process of delivery is dragged out, while more die. Therefore, it the

announcement of compensation, £11.8 billion, is just a figure on a spread sheet. We experience no comfort or evidence of commitment from the government other than the interim payment to a selection of 'recognised estates. The meetings take up our time, but there are no positive outcomes. If you look closely at the Victims and Prisoners Bill it does not mention estates, and only references a payment of '£100,000' and the word interim was removed.

11. I have specifically campaigned on issues relating to the care of those the state infected, the lack of consideration and respect shown to all carers, and the continued failure of the state to recognise and mitigate the impact. As the process unfolds, I have also been identifying discriminations and impacts on both those infected who have survived as well as estates, as I believe the government is downgrading even the original offer, which was in itself poor. I have also specifically argued for the rights of the estates to be recognised. I always felt from the beginning that terms like 'infected and affected', were specifically meaningless, and disregarded the dead. It was my belief that it was the government's intention to disregard the lives lost, and it was intent on profiting from the decades of delay.

12. The Support Schemes themselves were inherently discriminatory because the design of the scheme rewarded survival, whilst disregarding death. The state was responsible for killing children before they were even old enough to enjoy a first kiss or breaking up the marriages of victims by withholding not just the truth of infection, but how it had come to be in the first place and were then using the lack of marital status to deny their carers and their families the same or fair compensation. Simultaneously by refusing to accept responsibility there was and still is no specialist care provision. The support schemes are clearly discriminatory to carers, who are in the majority women, although many men have stepped forwards to care, and this is in breach of the Human Rights and Equalities Act's. The victims are often being left to die gruesome deaths for want of even basic state respect, and their families forced to witness and manage such horrid, terrible ends.

13. Like many of our community, I live in a perpetual state of moral and emotional outrage, which in turn has imposed significant physical impact over time. Perpetual mental distress manifests physically. It does not end because we continue to live in a country that treats the people it injured and killed with such disdain, and which segregates and imposes such inhumane suffering on victims and their families. I am aghast that even when the government claims 'it accepts the moral case' that it is still only applying morality on a selective basis.

14. My work largely involves copious amounts of research, and gathering of information, transcribing, and writing up that information and or writing letters to government ministers, and specific civil servants. I have also been involved in numerous so called 'Consultations', meetings either online or in person with ministers and or their officials. I have had 33 emails from the Infected Blood Response Team since the 24th of April 2024, and countless more from IBCA, leading to at least three meetings with Sir Robert Francis over the course of 2024 and one more recent meeting face to face for the Carers Panel on the 28th of January 2025 which I had helped instigate and or organise. I have also had one face to face meeting with John Glen on the 10th of May 2024, and two meetings with Nick Thomas Symonds, (11th of December 2024, and the 30th of January 2025). I have numerous letters of correspondence will all. I was also invited to two meetings with James Quinault, one that I could not attend on the 22nd of January because I was ill, and one on the 25th of February where I did attend. I recently co-authored and submitted a very rushed submission on Unethical Clinical Trials in Scotland to the Cabinet Office which they asked of us just before Christmas on the 5th of December with a two-week timeframe where we were given a deadline of 5pm on the 19th of December 2024 to complete. I felt this request for submissions was profoundly expressive of the lack of respect and consideration shown by the government towards campaign groups. It also demonstrates a carefully managed process, where the consultation is a technical operation, designed to limit our engagement whilst ticking boxes.

15. The governments subsequent dismissal of our submission on spurious and preposterous reasoning would in most cases, be a cause of profound dismay,

except that to us, this is merely the same disregard for facts, evidence, and or reasoning we have become accustomed too by the British Government. The government rebuttals are very useful as they demonstrate that the current officials in the Cabinet Office do not understand and have made no attempt to understand the experience of Infected Blood victims and their families. As always, we are given scant time to make any points, and in the main we never receive a proper response to questions asked. There is no recognition that I and others have endured considerable suffering and distress. They have not only not moved, it feels as if with each successive meeting that the scheme is further eroded. We are not only ignored, but we are also effectively told that they do not care or consider their role is to mitigate injustice, and that the government see's perpetrating injustice as its right.

16. It is my own, and everyone I speak with, experience that the government does not consider us at all. It calls meetings with very little notice, and it organises its consultations on the hoof so to speak in appearance, but it is probably also planned to prevent us from having time to lobby our MP's. For example, they have been drafting the legislation on the supplementary routes for months. Discussions I had with officials from the Scottish Government in August 2024 implied that officials had seen the draft of the second set of legislation being laid before parliament, but we are only given the legislation as victims just before parliament is due to vote, and given no time to scrutinise them, meet with our MP and therefore have any influence. As the government has stated that they 'do not expect those affected to start make a claim before the end of 2025, they could stagger the legislation and allow sufficient time to consult and involve victims. Instead, they use the imposed government set deadline to rush through legislation, with the rhetoric that we must not delay the legislation because the government is so anxious to get moving, whilst failing to employ and train enough assessors to run the scheme as expediently as the rhetoric.

17. Dealing with both the Cabinet Office and IBCA and all the submissions, the letters etc is practically a full-time job, and even although we all try so hard to be heard and to communicated, we are none the less disregarded, and they do not take on board anything we say. The consultation and all the governments

conduct does not just constitute just lip service, many of us believe that the real purpose of the meeting other than as a tick box exercise, is so they can work out our complaints, and use it as research in order to further block any attempts we might make to affect change. We also wonder if the purpose is to wear us out with engagement to prevent us more usefully organising more transformative democratic engagement. For example, it may be a coincidence, but after we made arguments about Equalities Law, the government made amendments to Equalities legislation arguing only people in the same category were entitled to equality, rather than it being a universal right. Why are we all given our labels, affected daughter, bereaved sibling etc, and distinguished as categories in the compensation scheme rather than treated as individual human beings with rights?

18. I have sat in private meetings with officials such as Brian Williams from the Cabinet Office, bared my soul, and my most private pain, to try to get through to the government, only to find everything I said, every point I made completely disregarded. More recently I tried to help IBCA set up a Carers Panel so they could hear from and consider the impact on individuals. Even though we have been talking about this for months, the dates been moved several times, then the date was fixed but the time changed, and no transport was organised. When I wrote directly to David Foley to raise my concerns on the behalf of carers, and to argue how inconsiderate IBCA are towards elderly people, who needed considerate travel arrangements and plenty of notice, he initially deflected, and did not acknowledge the concerns raised. After looking into the matter, David Foley found my criticisms were founded, and subsequently plane tickets were organised that showed consideration for the age and experience of participants.

19. Why this could not have been achieved much earlier, and or more consideration shown to the public purse in organising the panel much earlier, I cannot answer. All I can say is that IBCA did not show consideration to participants, and or to me specifically. As an organiser I had to field queries and calls from participants, even though I had no power to organise and or control the situation. At one point a staffer from IBCA even asked me to issue the invites, as if I was a member of staff, which I had to decline and point out, that this was the

responsibility of the host. On the day the Carers Panel was worthwhile, and I do not intend to criticise individuals working within IBCA, who are kind and pleasant, but the Cabinet Offices refusal to attend, demonstrates that the government has not even attempted to engage with Carers. IBCA are meeting with us, to understand the sensitivity that will be required in dealing with carers for the scheme not because they can change the scheme tariffs and design.

20. Recently when I helped organise a panel with Care Providers, of the 6 carers present, only one is supported by the support schemes specifically for providing care. One of the others was awarded because they were also directly infected, but they would not have received support payments as a carer because the individual had cared as a grandchild. This care is not recognised and/or considered by the support schemes. I understand that IBCA asked the government if they would like to attend, given that there has been no assessment or engagement with carers when devising the care award. The government declined to engage. I then asked the Cabinet Office to attend myself, and they did not even respond to my email. Therefore, we are currently facing care awards that are being further downgraded and eroded by a government that has refused to involve victims in the design of the original proposals made without any assessment, and now as they are downgrading them have refused to assess or engage with carers. This demonstrates not only disregard but worrying mismanagement.

21. At a meeting on the 25th of February, I had the opportunity to listen to GRO-D GRO-D on the behalf of the government seek to defend the Care Award. GRO-D GRO-D did not really offer a broader explanation that what was published. He described the Care Award as a calculation on a spread sheet. He demonstrated no knowledge and or consideration of the broader issues, and the direct experience of carer providers and people who are so Ill that they require care. I found myself saying out loud, ‘how dare you speak to me like that’. I shocked myself with my outburst. GRO-D defined the cost of care to its lowest denominator, the hourly rate of a care worker or the minimum wage and then argued that 25% should be deducted as we were not employee’s. The

explanation lacked any recognition of care or how care services are delivered and assumed that we, victims do not understand ourselves. Had commercial care been provided even by the council, the costs would have included, administration, holiday pay, public liability etc and been considerably higher per hour. Some care providers charge governments and councils between £100 to £45 per hour. The government insults us when it makes these statements and proposes such a low award for care and diminishes our experience by valuing it as the minimum wage less 25%. I think on a personal level that it offended me so much because it is an insulting award for care providers who have as we did, endured a living hell. They are also downgrading the value of care as the victims got sicker, arguing that the existence of antivirals was a magic wand, where everyone miraculously was cured, despite years of liver damage. Every victim of HCV is to have their care award downgraded whether they received antivirals or not because apparently the existence of a drug is justification.

I have argued for over a year that if the government cuts 25% that it must credit the amount to the National Insurance accounts, so as not to further discriminate carers. As it stands the government proposals deny carers the right to claim for lost income. They deny carers actual personal injury and autonomy awards, and on top of that the proposals even cheat carers of a proper state pension by disregarding that many victims will not have full national insurance records because they were forced to care. The Government has clearly not conducted any Equalities Impact assessment as the care award equates to basic discrimination because the compensation scheme is an extension of the existing discrimination endured by families forced to care for their infected loved ones.

22. We are making all these points, and just being ignored. It was very moving being at the carers panel, and hearing other carers talk about their experiences, and those of their loved ones that they cared for. The government though was not there to hear it and demonstrates its contempt for carers in its actions rather than words. It is really important for our community to have their experiences recognised. I have only ever put my head about the parapet, because so few

were willing to go public. I understand why because it does make one feel incredibly vulnerable and exposed.

23. The government have now decreed that infected survivors will also have their care award deducted by 25% and has decided that they can pay their own care costs from the existing support scheme funding, which disregards that the original conditions of the award in legislation is that the support schemes are free of tax and cannot impede on rights to benefits. Care support is a benefit, but we assume this will be denied. This implies that surviving victims are, rather than being 'compensated' facing a real term cut in the value of their support payments, as the government also proposes that those on the support schemes will receive less up front compensation awards in a lump sum. This again places carers in the same situation we were faced with, and is therefore not a remedy or a preventative measure, but perpetuating the injustice we suffered. This is intolerable.

Q2. What if any external support or assistance has been, or is, available to you and your colleagues in undertaking the work described above?

24. None. There is no support and or help on any level. There is no respect and or regard for the time it takes to make freedom of information requests. Then to trawl through detailed documents, and or go to meetings, only to have one's findings which I know to be factually correct, and the truth dismissed out of hand. We find the government so insensitive, obdurate, and unresponsive, that it is fuelling my and other campaigners existing depression and ingrained belief that no one actually cares and or has any respect. We are treated as a problem to be managed, and they do not even do that well.

25. I also find that the Haemophilia Society and SIBF are so underfunded and without any support that it is impossible for them to continue as they are, and if they continue it is only out of the compassion and kindness of many volunteers. SIBF is the most effective and universal organisation in Scotland, which brings together both whole blood and bleeding disorder victims. It holds a weekly forum, and also completes considerable advocacy on the behalf of victims. In

recent months SIBF have been focussing on HBV victims who are excluded from the support schemes. Not only is SIBF not properly funded or supported, its only worker, is effectively a volunteer. For someone as effective as Tommy Leggate, to go completely unsupported is a disgrace. I think it is bad enough that carers go unrecognised, and we are left to campaign despite the considerable emotional toll on us. At least one day there is an expectation we might, if we can survive long enough, receive some form of paltry compensation. This is not the case for Mr Leggate, who I sometimes fear is not funded or supported because he is one of the most effective advocates in Scotland.

26. Therefore, in conclusion, I do not perceive that we are supported by government. The Scottish Infected Blood Forum, receive no support whatsoever except some funding for zoom meetings, which is barely even adequate.

Q3. Please describe the involvement of people infected and affected in the decision-making regarding compensation (whether by Government or IBCA or both) as you have experienced it.

27. There is no involvement whatsoever in the decision-making process from either those infected and especially those affected. On the rare occasions where we are allowed to speak with, or meet with government officials or IBCA, time is rationed, and we are only given a few minutes to speak. As one example, in June 2024 after the new government had been elected, we were invited to attend one two-hour consultation meeting with Sir Jonathan Montgomery, Sir Robert Francis, and some officials from Whitehall. We were allowed to make a written submission [WITN2632088] beforehand and told before the meeting we would be allowed five minutes to speak. I prepared a written submission after spending considerable time, scrutinising the recently published proposals. I identified in my submission, that despite those affected constituting at least 40% of all those impacted and the estates of the deceased [WITN2632088], that we were only afforded one of the four meetings, and were automatically being given less time to discuss our concerns by Sir Robert and the government.

28. At the meeting I described the impact of suicide on my family and the mental health toll of those affected. I asked why there was no consideration of the mental health impact on the bereaved families. I asked why when relatives had personally been the victim of research, which they had not had the opportunity to give informed consent to participate in why was the government refusing to compensate affected people for the loss of the right to have children and or for actual personal injury?

29. Other affected people spoke up who were in the meeting, and it was felt, that we had expressed our discontent with the government's proposals. A few weeks later we were sent a document called 'Final Feedback Document' [WITN2632088] but everything we had said was written out of the discussion. It was as if the meeting had not taken place with those affected. We had been written out of the document. I made a Freedom of Information Request to ask to see different versions of the document [WITN2632089], this was denied. I then appealed the decision, this too was denied, leaving my only course of action as to make a complaint to the ICO. I have been unable to do so, because they will argue that it is 'a policy decision. I am therefore waiting until after the legislation becomes law, to make the Freedom of Information Request, by which time the value of the information will be diminished in terms of influencing said policies.

30. During this period, I studied the existing Public Sector Equality Duty documents for the support schemes, and the most recently published PSED documents for the current government proposals [WITN2632089]. All were inadequate and inconsistent with what I understood a PSED assessment to be involved. I then wrote a complaint directly to Sir Robert where I listed all the issues we had raised, and which he and his staff had completely ignored. There was not a single recommendation he had made, that related to or showed he had listened to those of us who are affected or who represent estates. I did eventually receive a reply from Sir Robert, which did not address or mitigate my complaint.

31. I then had a further meeting with Sir Robert and his team on October the 17th, 2024 between 10- 11am. I was staggered, that I, as an individual was afforded the time of Sir Robert, David Foley, Rachel Foster, Emma Browne and one other. Accordingly, I asked why I had been given the opportunity to meet and have my own meeting, which I was astonished by. Sir Robert explained that they were specifically interested to hear my arguments regarding Equalities, since I had been sending the Cabinet Office Freedom of Information Requests. This is one of the reasons why I believe these are not consultations, but opportunities to hear our arguments so they can work out how to circumvent them or fact-finding missions.

32. I felt that the whole meeting was a waste of time, describing it to my sister Rachel as feeling as if I was raining on a waterproof and that I could not get through to this group of individuals. It is always the case after every meeting I have, that I feel wasted, empty, and bereft and that my grief about the suffering poor dad and all those other victims endured, is disregarded.

33. We also objected strongly, (and I made these points directly), in a meeting I attended with the Getting It Right Group on the 17th of December 2024, with Sir Robert, David Foley and Rachel Foster, that in November 2024, IBCA organised us into different categories of victims, and then asked us, who should be prioritised for compensation. I told them it was completely unedifying for them to take a community they know are divided and to then pit them actively against the other.

34. In the meeting in November, I attended with Siblings and other affected people, we were told by IBCA staff that those infected who had survived were advocating that only they should be prioritised, which caused all of us considerable distress. We were obviously mindful not just of the date of death, where many victims had died without receiving anything, and that they had elderly partners or parents, or children, who were grieving and or who had suffered, and we obviously advocated that all vulnerable and elderly should be prioritised. We were also told in the same meeting that the government believed

there were between 300,000 to 100,000 affected people. I raised this figure in the meeting of the 17th and argued that these figures seemed as preposterous, and they were without reasoning. I understand many of us have challenged these figures. We believe the government is spreading anxiety again. Many of us are arguing that the government should register all affected and establish the actual numbers. David Foley specifically said they would be concerned that this would create an entitlement. We argued it would only give the government accurate figures.

35. On the way back to the car I was informed that the consensus from the prioritisation consultation was that the majority of victims wanted all vulnerable, elderly and sick people to go first, regardless of their status as an infected or affected person. Despite this IBCA continue to prioritise those on the Support Schemes and we still await legislation for those affected. Of the existing claims being processed as test cases we understand IBCA have not prioritised the terminally ill.

36. On the first day of the launch of IBCA's Facebook page, I am told that predictably those groups, all started an online argument, where some of those that had survived, tried to argue that the dead were better off than they were, and were not entitled to compensation, and that only those on the support schemes should be entitled to receive compensation. I do not understand how it can be that one group of victims, should feel entitled to make decisions for another, or that they would be qualified in moral reasoning to do so. The law is the law, and it should not be possible for the state to be responsible for the death of a person, and then use their death as grounds to save themselves compensation and to be aided and abetted by those who feel they will be more financially advantaged if the dead are disregarded.

37. Bereaved families will not accept any reasoning where the scale of the deaths is used to justify the breadth of the tragedy, only for those to trample over the dead and their families, because it is convenient and expedient to do so. However, we are now hearing in the form of government fact sheets that the government is going to legislate that no affected person can have a claim until

the infected person they are attached to has been assessed. The government are also legislating that unless an affected person's claim is actively being assessed that should they die, their claim will die with them. This allows the government the potential to delay registering those affected, and in doing so delay instigating a claim, which means the government can financially benefit from delaying an affected person claim. This may explain why the government delays actually registering affected people, because it is seeking to profit from the delays it creates.

38. I cannot see how this is an appropriate response to forty years of government obfuscation that they continue to deny the rights of all those that died as a result of the government misconduct that these same people should be pushed to the periphery again. I do not blame those that survived who advocate and support these policies, because they government has created these conditions and has deliberately pitted families against the other, and those that have died from those that survived in its continued policies of segregating the suffering of victims around dates of death, dates of birth and marriage certificates. I find the governments behaviour not only completely unedifying, but it demonstrates how little regard is has for the finding of the Infected Blood Inquiry.

39. We are also dismayed that despite providing detailed evidence of the exploitation of Scottish patients to test and develop Z8 and Liberate in Scotland as evidenced in both the Penrose and Infected Blood Inquiry that the Cabinet Office as chosen to disregard our submission, the findings of the Infected Blood Inquiry cited by us, and is arguing on spurious grounds that on the latter Liberate that it can disregard the inquiry's findings, arguing that consent was secured, even although the inquiry and our own findings demonstrate consent was not secured in an informed sense and was therefore unlawful. They are also arguing post 1991, that all blood products were still infective, and that therefore it did no additional harm to use babies and small children to test products on in a clinical trial.

40. The responses I have received in recent correspondence with the Cabinet Office only further affirms that the decision-making bodies are prioritising policy

'box-ticking' over engaging with considered and genuine feedback from those they have invited to help shape the Scheme. I refer to an invitation I received to meet with James Quinault on the 25th of February 2025 on the 18th of February 2025. I was told by a member of the IBI response team for the Cabinet Office that: a) we could not affect the content of the regulations laid in draft before Parliament as they (the government) cannot make further amendments to draft regulations as they have proceeded beyond the technical briefing; and b) a draft question would have to be provided one day before the meeting, otherwise we would be responded to 'in the normal way'

41. One of my issues with contacting the Cabinet Office is that they often do not respond to the various letters and submissions I have sent to them in a timely manner themselves. I also have concerns over the responses I do receive from the IBCA. For example, in the invitation I received to address questions to James Quinault, I was told that the government cannot make further amendments to the draft regulations. On a technical level, this response is incorrect. If parliament requests amendments and or additions to the regulations as part of any debate and or the statutory instrument committee recommends the regulations be changed, then these regulations surely could be changed because they are not yet law and won't be until the 31st of March.

42. Additionally, the Cabinet Office's response to me on the draft regulations here demonstrates another issue I have; the Cabinet Office and the IBCA can be inconsistent and, I suspect, misleading at a policy-level. Counter to the information I recently received from the Cabinet Office, the minister, Mr Nick Thomas-Symonds, has stated in parliament and in writing that he has reserved the right to amend the draft regulations, should new information come to light. The question arises as to the extent the government has even recognised the information that already exists? What does 'new information coming to light' mean? How does it come to light? The Cabinet Office's disregard of the concerns expressed by those invited to assist the Scheme contradicts the minster's assurances. For example, numerous concerns were raised about the proposed compensation scheme in the Getting It Right document, which the

regulations show were disregarded. A letter was sent by the IBCA which was followed by a meeting between IBCA and the Getting It Right Group on 17th December 2024, which I attended in person. This meeting did not respond to the concerns that were raised with the IBCA – it only sought to address the IBCA's functional role and not discuss the structure and design of the Scheme. Sir Robert also explained that the response IBCA sent was not drafted by him, but government lawyers. We were told by IBCA that we would be receiving a separate response from the Cabinet Office which we never received, and the Cabinet Office has just ignored what was a detailed letter from a number of campaign groups under the Getting it Right banner.

43. This leads to my overarching observation that responses from the Cabinet Office 'in the normal way' shows that nothing has changed post inquiry. The government is in no way transformed. We should be involved in determining how we are consulted with and the form of engagement and timeframes we are provided with. When we are asked to discuss amendments or changes to be made to the Scheme, we should be invited to have a proper meaningful discussion. I actually feel that the governments consultative process is in effect, abusive and a form of emotional terrorism. The only emotions are ours.

44. During my recent meeting with Mr Quinault et all, when I was explaining the injustice of victims not being able to claim for the financial loss of inheritance as some victims will have been too ill to manage inheritances like our dad was, the response I received directly from my Quinault was ' I am sorry that does not work for you' and effectively 'take us to court' because he argued that the tariff system was too broad to include the loss of inheritance, even though inheritance is the foundation of wealth in the UK and that there would be no route in the supplementary route to claim for lost inheritance and or from the other injuries and impact from the infected blood scandal.

45. Give the recent ordering of who will be prioritised, and the refusal of the government to allow infected and affected people to register, it appears, to many, that the policy of attrition has not changed, post inquiry report. The government claim this is not true, but as I stated directly to James Quinault,

their argument that registration 'would create an entitlement' demonstrates they fear if we register and establish that we have a claim, that they will have to pay us compensation and stop benefitting from attritional policies as they have done for forty plus years. The refusal to allow HBV victims onto the support schemes, and then leaving those directly to the end of the appalling list of IBCA's prioritisations will lead many more to die without justice.

Q4. Please describe the principal concerns (if any) which you have in relation to the involvement of people infected and affected in the decision-making regarding compensation (whether by Government or IBCA or both).

46. There are so many concerns that the gap between what should be and what is, feels insurmountable and overwhelming.

47. First, we have been excluded from any involvement in designing or being part of a compensation scheme. I remember on the 10th of May that John Glen MP had explained in our meeting his astonishment at how little had been achieved by his predecessors, that he had taken the advice of the Civil Service, appointed Sir Jonathan and excluded us, because he was acting with such haste that he felt he would miss deadlines for the Victims and Prisoners Bill to have involved us. Given the years of delay and wasted time, it was quite clear that the Conservative Government would not have acted at all, had parliament and the opposition specifically and abstentions from key Conservative MPs did not force their hand by passing the Victims and Prisoners Act. However, when the Labour Government eventually published what little information was available about the work of Sir Jonathan, and his 'experts' which my research showed, was very narrow.

48. Secondly the expertise gathered together by Sir Jonathan, amounted to knowledge of specific viruses, and there was no one with expertise in Mental Health, or Social Care of infected blood victims, and no expertise in the lives of those affected. They do not even seem to make use of the inquiry's expert reports. I researched all the named 'experts' and their expertise was limited. They only involved one of the professionals used to draft the inquiry's investigations. At times campaigners refer to inquiry special reports and the

government end up admitting they have not read what are key reference documents produced by the inquiry. Therefore, not only is the tariff system itself discriminatory to those infected and deceased, it also shows scant consideration of the impact on those affected. We object to the tariff system, which discriminates between viruses. We also object to the lack of regard shown to HBV victims who are not recognised by the support schemes, and are also not being prioritised by IBCA, despite the severe health impact. The support schemes in refusing to recognise specific infected individuals, and also to recognise all care providers such as parents, children or siblings who provided care segregate suffering. Those on the support schemes, insist they must continue, because an entitlement has been established, and whilst they should continue, the schemes should be inclusive and not tools of segregation. It is also a worry to see that the government's proposals are actually eroding the value of the support schemes.

49. Equally there is no regard for elderly parents and or widows who are not accepted on the scheme or elderly children. The government knows it discriminates, and that it continues to do so, because now they are saying any bereaved after the 31st of March 2025, will not be eligible for support payments, thus even segregating those who share the same status, just because of a date of death.

50. We object also to the tariff system for those affected in making it such that the actual injury of an affected person goes unrecognised. We are to be given either £8,000 or £12,000 for personal injury even though there will be no assessment of our actual injury. Therefore, those of us with official diagnosis of PTSD, will go uncompensated and will not be awarded the £85,000 tariff identified in the Francis Review.

51. The government cooked up the Care Award without any consultation with those that required care and or those that delivered care. It has come up with mandatory scales of average hours it expects people to have required care, which have no basis in fact and or in evidence. It also states that the palliative care period would only last 6 months, and there is no mechanism in the core

route to specify or evidence actual care provided in the core route. I have received not even an acknowledgement of my point. This means that every person seeking to actually claim for care provided must go down the supplementary route and we are still no further forward in understanding what the supplementary route might be or look like because we have not had sight of the draft legislation, and the core legislation was withheld completely from us in the first place. As stated, the Cabinet Office are now also decreeing that all care costs should be reduced after the introduction of antiviral drugs, regardless of whether a victim a) ever received those drugs, and b) even if the government's refusal to prioritise victims it infected for antivirals, then died waiting for the drug. Even though many issues could be remedied by a simple tick box, the government refuse to consider any appeals in this respect. I have been arguing the same points for eight months and I am now at the juncture where I believe we must take specific forms of alternative actions.

52. At the meeting with James Quinault on the 25th of February, I was treated to a technical explanation by GRO-D, who is Head of Economy Frameworks Policy at the Cabinet Office, His explanation effectively regurgitated what I already knew from the published documents, but I felt he spoke to me as if I was a child, and that he was explaining something technical. What I actually heard was that there was no consideration of anyone's experience. We were reduced to units.

53. This in effect means that the Care Award, rather than compensating for the cost of care, become a derogatory award, that will in the future be just as harmful as it was for the families of the deceased. The families will be unable to claim the basic social care support we received, and it will diminish the value of the support payment for day to day living costs. It also leaves the carer in the same position as being unable to work, but now unable to be compensated for future care unless he or she is considered by the person needing the care. Families will again be forced to live on one income.

5. Please describe the impact upon you of the matters set out in 1-4 above.

54. I am stuck in a perpetual state of outrage and distress. I am unable to get over my PTSD or the health problems associated with the distress of caring for my dad, because the trauma and the abuse has not ended. All I do is make representations which go ignored. It is very difficult to recover from stress when the source of stress never ends, and long-term stress has manifested on my physical health. My career as a film maker has been further eroded. I, should feel privileged to be consulted and invited to make representations to the government. When I was looking after my dad, I had the crushing feeling, that no matter what I did, or how much I exhausted myself that I could not change anything. I could not prevent his suffering; I could not alleviate his pain. Then when he died, I had to find out what happened to him and to do my best to honour dad and to investigate and research his medical records. Engaging with the government is a waste of time and actually harmful to ones life.

55. I never feel there is any genuine empathy or understanding. We are just treated like a problem to be managed. I could spend the rest of my life arguing with the government and they would not care and or show any compassion. I have noticed this same feeling amongst colleagues and fellow campaigners, and I know that all the families excluded from support, feel this more keenly. Although we were one of the families who received the first round of interim payments to the estates, divided between one family, the way it was managed, we felt constantly in the dark. We did not believe we would get the award even when we were sent written confirmation. It was only when the interim payment showed up in the executor account, that we could believe it. within hours we had distributed the funds. I felt like I blinked and by the time I had paid off all the debt I had accrued from being sick and unable to work that they money was gone, and that the gaping financial hole left in my life, was not even touched.

56. We have no idea when we might receive compensation for what we all suffered and for dad and his life. We just feel we have climbed a mountain bare foot, only to find another mountain ahead. I have this sense that I live in an immoral country where justice is only something bestowed on the few, and not a universal right. Justice and compensation are only afforded to those with HIV and those the government decides, and it is not universal, and the dead remain

discarded. This is said not to discredit those with HIV or who have died from it, as we still do not think they are receiving enough compensation. Rather the government has offered only those with HIV larger sums, to give the public a good headline and to be seen to be doing something, while the rest of the HCV and HBV cohort are treated as lesser.

6. Please describe the impact you perceive the decision-making regarding compensation (by Government, IBCA or both) to be having on people infected and affected, and why.

57. It seems to me that the response from the community is mixed. Those on the support schemes, continue to receive annual payments, and having fought for those payments to continue, know that they will be able to survive because they will continue to receive support payments whilst they wait for the invitation to apply for compensation. Yet this group are fuming, especially at this juncture where people are beginning to register how prejudicial these regulations are. We feel that we are not even at the beginning of the end, or the end of the beginning, but just in another long, weary stage, where the government continues to segregate the suffering of victims, continues to leave people to die without justice, and talks in rhetorical terms, but in its actions, shows a profound cynicism, which to my view is the root of this scandal. What is also coming to light, is that the government is now looking at ways to disadvantage those on the support schemes by giving them significantly less upfront compensation and forcing them to pay costs later down the line.

58. It has also come to light that the government by setting a cut-off date for registering on the support schemes is preventing people from registering on the support schemes because people require evidence. Victims can only receive the information from the Health Service, and some victims have been waiting for over a year for records and still do not have them. One person I know missed out on receiving an interim payment because her parents' health trust will not give the relevant records. The Government as perpetrator being left to manage the solution, is not working for anyone. We would not ask a serial killer to design

and deliver the remedy, but we are in a totalitarian context where the government is responsible for injury and allowed to dictate in perpetuity.

59. Despite the Inquiry's report, nothing has been learned and only a smattering of people have been compensated. The minister said in a meeting on the 11th of December, that he was determined that those affected could submit claims from the 31st of March, in the meeting on the 30th of January just over a month later, this had changed to 'before the end of the year'. We cannot wait for another year, and we know that even when those affected can claim on the behalf of estates, that we could be waiting for years. Nobody cares about our dad or his life, except us. It is apparently acceptable to kill people in the UK and to then have the perpetrator act as judge, jury and the determinator or compensation.

60. There is nothing arm's length about IBCA. All the staff with the exception of Rachel Foster all have Cabinet Office email addresses including David Foley and Sir Robert Francis. IBCA say they cannot make decisions on compensation, yet the government refuses to consult and holds limited meetings with campaigners but does not actually consult. I cannot see what has changed.

Q7. Are there any particular steps or measures which you consider could be taken by Government, IBCA or both to alleviate any detrimental impact upon you, and/or the infected and affected communities? If so, please set them out.

a. The government could establish a committee of those infected and affected to work with the government to iron out and sort out the problems with the compensation scheme.
b. The government could facilitate and organise elections, so that those negotiating with the government, are not those who are self-appointed, or self-determining to represent the community. We could write statements and subject ourselves to elections, and make sure also that there is a proper consultation mechanism where those represented can use survey monkey and or vote on specific issues.

c. The government could hold joint meetings with IBCA where they consult and give campaigners access to decision makers. These meetings could be published and scheduled well in advance and the meetings could be recorded and broadcast so that the whole community could see what is being said about them in their name.

d. The government could appoint a junior minister with the sole responsibility of consulting with and engaging with campaigners rather than these rushed meetings where we are given less than 5 minutes to make our points, and then what we say goes unanswered.

e. The government could set up a committee of MP's and Lords who represent constituencies of impacted families, to scrutinise and oversee the work of the compensation body. The committee could call evidence and ask witnesses to come forward. As it stands the government is calling debates at short notice and most victims do not even feel they are being properly represented by their new MP's.

f. The government should also legislate so that victims can have an ombudsman and or regulatory body to take complaints to. The correspondence from Baroness Newlove demonstrates we have no regulatory framework and only have open to us the magnanimity of our MP's which is not a consistent right.

g. The government could establish surveys and or consultations that are fact based and have statistics and or facts which could be published, rather than these talking shops which are not recorded or minuted, and which one cannot prove what was said or what was agreed. For example, it could establish a survey for carers, to establish what work was involved and what timescales or what the personal cost is to victims and carers specifically, as we have done: https://www.surveymonkey.com/r/infected-blood-carers

h. The government should set up an independent compensation authority which is answerable to parliament and a committee of both Lords and MP's. The Cabinet Office, and the governments should have no oversight. The government could be allowed to make representations to the committee, but the committee must be above reproach and made up of a cross section of political parties and constituencies from across the four nations, and also to have lords that represent the breadth of the political and regional perspective. This has not happened, instead all the staff of IBCA with the exception of Rachel Foster have Cabinet Office email addresses. IBCA is used to deflect from the Cabinet Office who not only disregard submissions but use IBCA as a shield rather than a vehicle for genuine consultation and or change.

i. We should not be dealing with James Quinault or GRO-D or other officials who has no qualification or experience of dealing with or supporting Infected Blood Victims. Why are the Cabinet Office and the civil service, who have been so badly criticised by the inquiry allowed to be directing the solution, when they are defined as the problem? The government needs to set up a genuinely independent body.

j. The least the Cabinet Office could have done is actually read the Inquiry's expert reports and or actual report, but it clearly has only selectively read it and is making up its own rules.

k. Registration and therefore acceptance of all claims for infected survivors, deceased infected persons and all those affected should be instigated as a matter of urgency. The government must not be allowed to segregate suffering and to use delays as an excuse to deny claimants justice.

l. Interests at an acceptable level must be paid to all claimants pushed to the end of the queue by IBCA and the government.

m. The government must share proposed legislation and involve victims and their legal representatives in the drafting of all legislation related to remedy, compensation and recommendations on infected blood.

n. Claims should be processed in a way that prioritises the vulnerability of claimants. Therefore, the date of birth of the claimant, the date of death of the victims who has died and the condition of health must be the only tools to prioritise victims for compensation.

o. The government must prioritise and appoint at least 500 claims managers as a matter of urgency and not the 20 it currently has which is a disgrace given that the legislation was put through in August 2024.

p. The government must ensure that legal representatives are allowed to represent their clients, free from Cabinet Office interference, and or restrictive contracts. Legal representatives must be allocated the hours to help prepare claims, offer guidance to claimants and also to check with and challenge all claim offers before the claimant is forced to accept or appeal an offer from IBCA.

q. Figures should be published showing the difference between an IBCA offer and a revised offer once a legal representative has checked and scrutinised the offer. IBCA should anonymously publish these figures so that claimants can see with ease which law firms are offering the best representation.

r. The government should pay interim payments to those being left to wait and must be forced to pay interest for every delay.

s. The scheme should be extended beyond 6 years to prevent the government profiting from delay's it creates.

t. All affected people must be registered and all dead, so that the government cannot profit from its own delays. This is said elsewhere but it is worth reiterating given that the inquiry has created this context by insisting the claim dies with the affected person, which has now led to the government exploiting the inquiry recommendation to its own benefit and not that of victims.

u. The government should offer an award for bereavement and for death. The cost of life is not recognised in any of this alleged compensation scheme. The cost of grief, as in the impact on those bereaved remains unrecognised.

v. I lastly think all campaigners should be given an award to compensate us for all the time wasted. I feel between a rock and a hard place. I have always felt, where I am ignored regardless of whether I engage or not, and I live in fear that if I stop engaging, they will have beaten me into submission. At the same time, I have to defend my family and my late father even although I find it is not only a waste of my time, my life, but that it further erodes my sensibilities and leaves me with only bleakness and heartbreak. I believe I live in a country which even when confronted with its own appalling behaviour, is incapable of change or of learning any lessons and that as a victim that I am perpetually disrespected and disregarded.

Statement of Truth

I believe that the facts stated in this witness statement are true.

GRO-C

Signed

Dated ______10th March 2025______________________

Table of exhibits:

Date	**Notes/ Description**	**Exhibit number**
26/04/2023	Letter of complaint from Justine Gordon-Smith to Jeremy Quinn MP in regard to estate interim payments	WITN2632086
05/11/2024	Letter from Baroness Newlove of Warrington to Justine Gordon-Smith	WITN2632087
06/2024 – 11/2024	Exchange of correspondence between Justine Gordon-Smith and Sir Robert Francis between June 2024 and November 2024	WITN2632088
01/08/2024 – 20/09/2024	Exchange of correspondence between the Freedom of Information team at the Cabinet Office and Justine Gordon-Smith	WITN2632089